

Bridging Health and Developmental Disabilities Worlds: Which Data? How?

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MEDICINE *of* THE HIGHEST ORDER



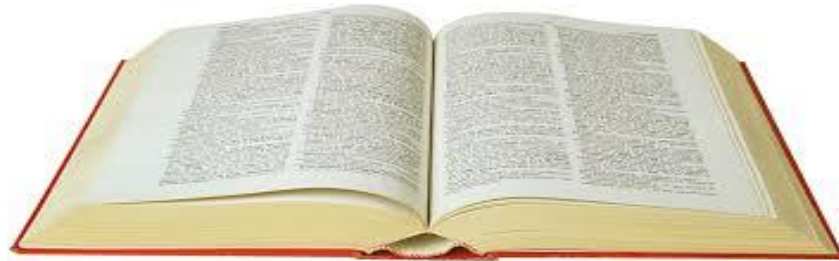
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I have no disclosures to report



Definition: Health Disparities (Healthy People 2020)

Differences in health due to racial, ethnic, religious, sexual orientation, socioeconomic, gender or **disability** status of a group of people (previously termed “Inequities,” which now more often refer to differences in access)



History Lesson #1: People with Intellectual Disabilities in Institutions

Norway, ~1935

- Ferric Chloride Testing of urine of 430 institutionalized people reveals 8 with PKU

Willowbrook, 1972:

- Crowding
- Inhumane Conditions
- Hepatitis Research
- Robert Kennedy and Geraldo Rivera
- Better Health Care Through Litigation

A Positive Ferric Chloride Test in Patients With Untreated PKU

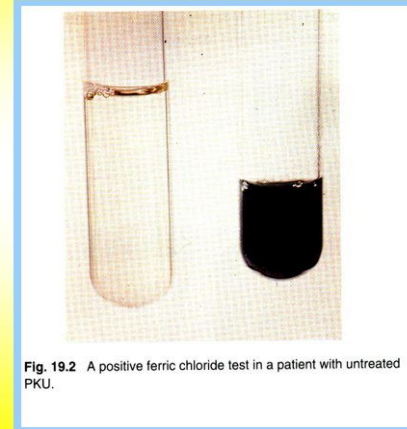
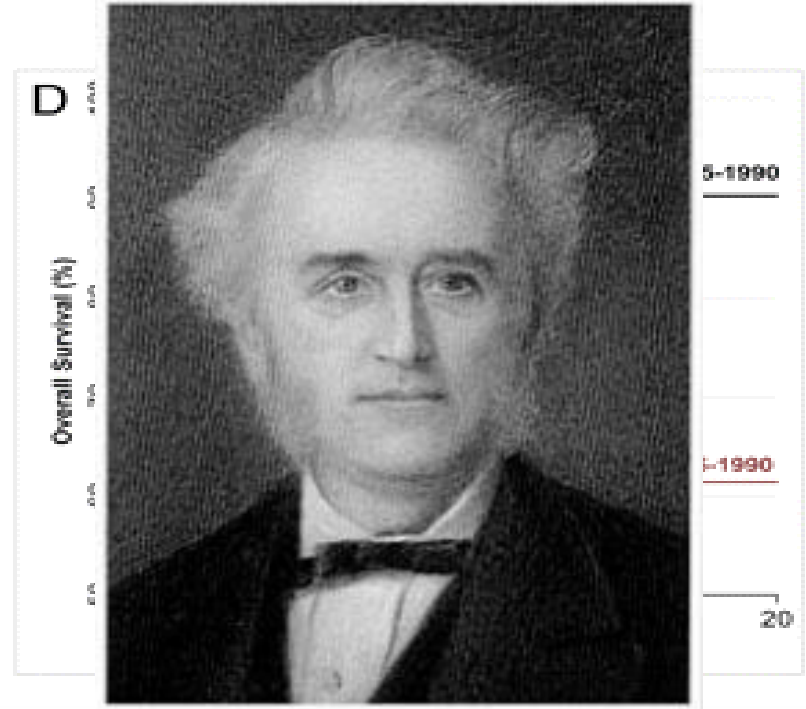


Fig. 19.2 A positive ferric chloride test in a patient with untreated PKU.

History Lesson #2: Down Syndrome Through the Ages

John Langdon Down, 1860

- Notes similar features in >10% of his patients at Royal Earlswood Asylum for Idiots
- Theorizes evolutionary “regression”
- Terms the condition “Mongolian idiocy”



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Challenges to Data Gathering

- Health facilities don't code for IDD diagnoses
- DD system doesn't keep good accessible health data (paper records)
- Medicaid data inconsistently accessible
- Health data and functional data in separate places
- Confidentiality issues
- Bureaucratic impediments

Health After De-Institutionalization

2002: Janicki, Davidson, et al

- 1371 Adults over age 40 living in “Group Homes” of 4-15 adults in Western NY;

Reporting by residence nurses

- Mean age: 53.5 +/- 11.1 years
53% Male
55.8% Obese
- Comparable to NHANES III data, except in
Hypertension & hyperlipidemia
Musculoskeletal disease
- **16% Hospitalized in past year**
30% ED use in past year



Dental Survey: 2013

Identified significant disparities in oral health for people with IDD in Finger Lakes region, based on surveys of dentists and of group home providers.

Results:

New training options

IDD Smilemobile

Special Olympics
Special Smiles®



How big a population? Nationwide data

- Pros

- Nationally representative
- Diversities acknowledged (regional, cultural, ethnic)
- Good for broad strokes, satisfaction, etc.

- Cons

- Often based on patient/family reports -> inaccuracy in diagnoses
- Limited medical data, limited functional data
- Often a chronologic snapshot; less option for tracking trends over time

Doubling Down: Health Disparities in People with IDD from Minority Populations

Mangaña et al, 2016: MEPS / NHIS dataset analysis

- 1131 Adults with IDD, nationwide
- IDD identified based on self-reported functional and diagnostic reporting (MR/ID, CP or other developmental problem)
- Compared people with IDD +/- minority status and people with minority status +/- IDD

People with/without IDD	Non-Latino White	Non-Latino Black	Latino
Fair/Poor Health	23.2 / 3.4%	40.6 / 7.0%	44.9 / 6.6%
Fair/Poor Mental Health	24.4 / 3.9%	37.8 / 4.5%	42.3 / 3.8%
BMI>30	32.7 / 24.5%	39.2 / 36.3%	40.3 / 28.1%
Diabetes	5.3 / 4.3%	8.6 / 6.7%	10.9 / 5.3%

Policy Advocacy Opportunity: People with IDD as a Medically Underserved Population (MUP)

HRSA identifies MUPs based on a score based on:

- ratio of primary care physicians to population;
- infant mortality rate (IMR);
- percentage of the population which is age 65 and over; and
- percentage of the population with incomes below the poverty level
- Geographic delimiter:
 - Local
 - State
 - National?
- Need: Data comparing population with IDD to comparable group within geographic area.

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Special Olympics: US Data

Table 1. Comparative health indicators between Special Olympics athletes and the general population in the United States (2007-2014)

Indicator (Age)	Special Olympics athletes (%)	General population (%)
Mouth pain in Special Olympics athletes and general population (pain in face and jaw) (18+)	11.7	4.8 ¹
Untreated Tooth Decay in Special Olympics athletes and general population (18-64)	25.6	23.7 ¹
Missing teeth in Special Olympics athletes (missing teeth) and general population (broken or missing teeth) (18+)	32.7	16.9 ²
Hearing problems in Special Olympics athletes (Failed puretone hearing exam) and general population (any hearing problems) (12+)	29.6	16 ³
Exposure to second hand smoke in Special Olympics athletes (self-reported) and general population (serum cotinine levels 0.05-10 ng/ml) (12+)	36.2	25.3 ⁴
Obesity in Special Olympics athletes and general population – (BMI≥30) (20+)	42.3	35.5 ³
Overweight or Obese in Special Olympics athletes and general population – (BMI≥25) (20+)	73.7	69.1 ³
Sufficient Aerobic activity in Special Olympics athletes and general population. (3 or more days per week) (18+)	64.2	49.6 ¹
Insufficient Aerobic activity in Special Olympics athletes and general population (1-2 days per week) (18+)	31.1	20.2 ¹
Inactive - Aerobic activity in Special Olympics athletes and general population (No days per week) (18+)	4.7	30.2 ¹

How big a population? Local data

- Pros
 - Useful for local resource allocation or advocacy
 - Eliminates regional differences
 - Available “for the asking”
 - Retrospective, snapshot, and prospective data sampling
 - Medical, functional, and service type data
- Cons
 - Smaller sample size
 - Less generalizable

Strong Center for Developmental Disabilities: Western New York's UCEDD

- SCDD focus areas: Education / Employment / Health / Leisure / Recreation
- Health Disparities Focus
 - Identify and address health disparities for people with I/DD
 - Optimize community-based care to reduce disparities and health care costs
 - Part of Medical Center-wide effort to address health for people with IDD

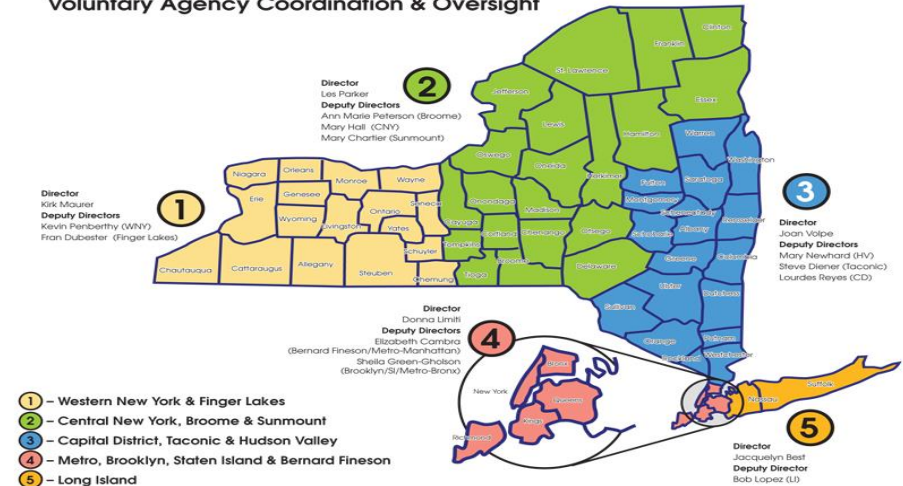
Access to Health and Dental Care

- Establish baseline of access to health and dental care for people with IDD in Western NY

- Who are the providers and dentists who see people with IDD?
- How far do people travel for care?

5 Developmental Disabilities Regional Offices Voluntary Agency Coordination & Oversight

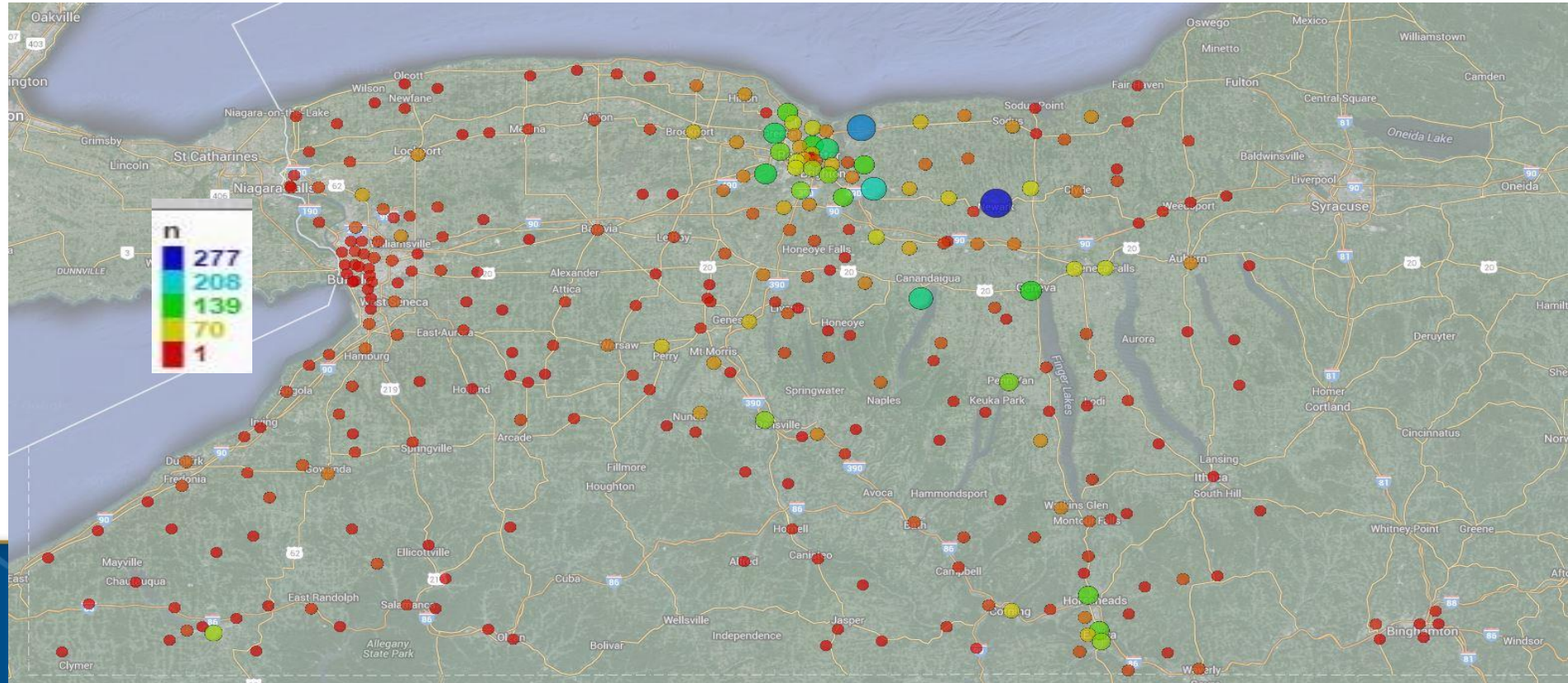
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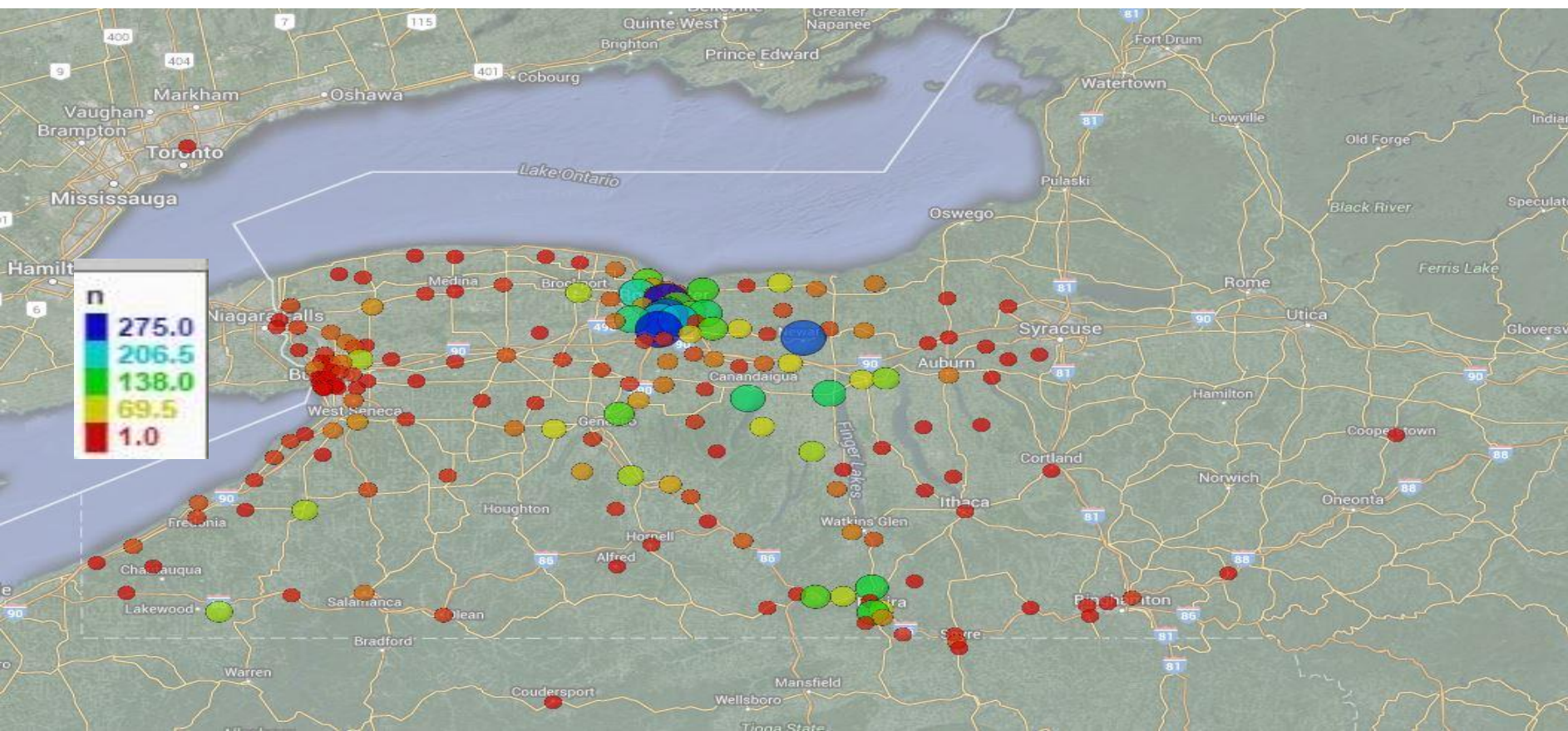
- Brief web-based survey of Medicaid Service Coordinators in 21-county region in NY
- 6,958 records
 - 5,553 via survey; 1,405 direct from 1 agency
 - (1,774 records provided direct but incomplete)

	Pediatric (0-20)	Adults	Total
Female	262 (4%)	2405 (36%)	2667 (40%)
Male	1173 (18%)	2846 (43%)	4019 (60%)
Totals	1435 (21%)	5251 (79%)	6948

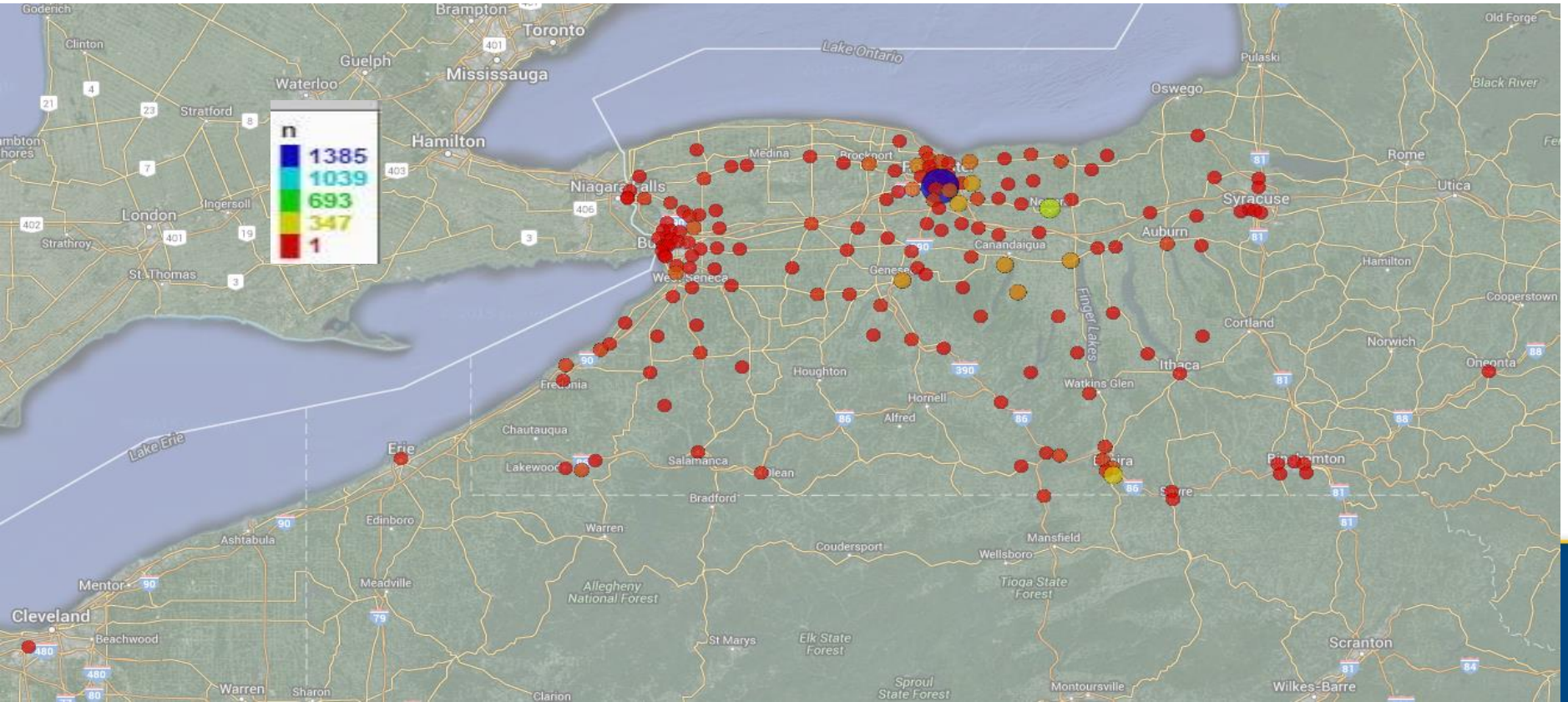
Where the people are



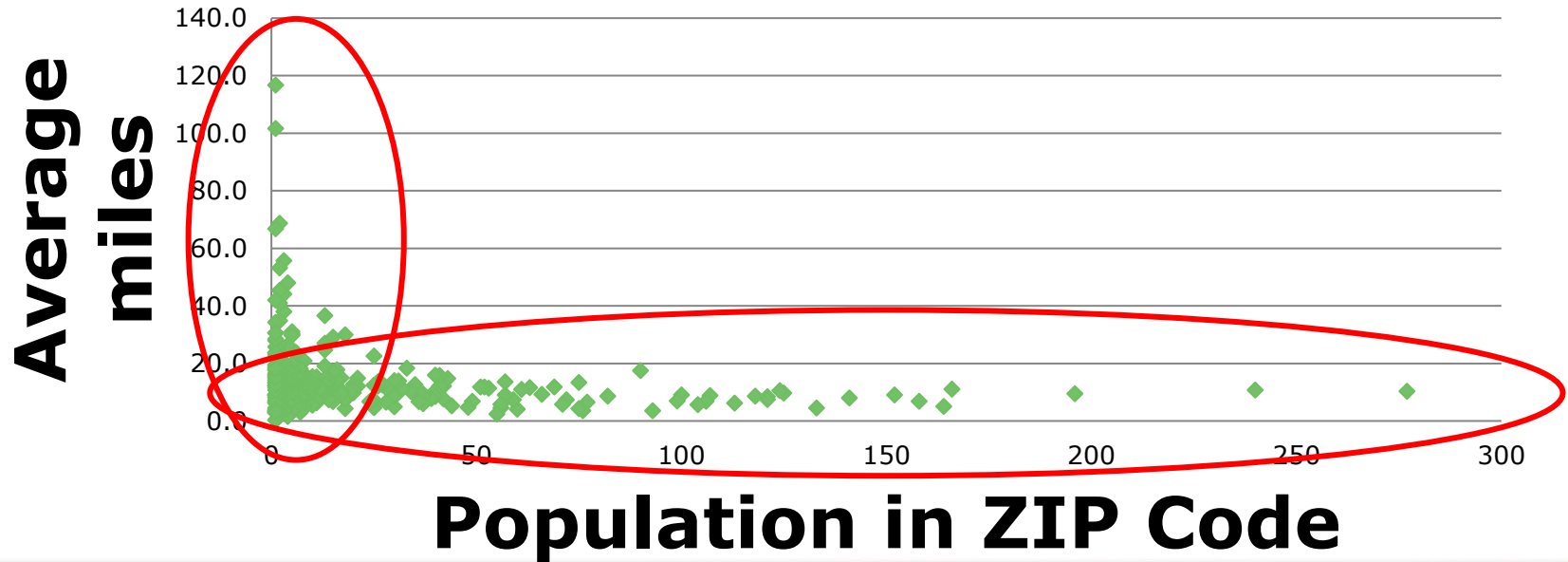
Where the primary health providers are



Where the dentists are



Average miles to PCP by population in ZIP Code



SUCCESSFUL TRANSITION FOR PEDIATRIC TO ADULT SERVICES

- Many adults with special health care needs have difficulty making the transition from pediatric to adult health services.
- Clinically, it has been observed that individuals with behavioral challenges may have even greater difficulty than others in connecting with adult health services.

Purpose

- Explore factors associated with successful transition and transfer to adult health services for individuals with IDD and other special health needs

Hypotheses: Individuals with IDD and significant behavior problems...

- Will be less likely to have successfully transitioned health care to adult providers
- Will be more likely to have dental work under general anesthesia

Methods

- The Epic i2b2 data tool (now called SlicerDicer) used to extract de-identified data from patients served at URMCC between the implementation of Epic and 9/30/15, when ICD-10 coding was instituted
- Subjects were patients age 12-30 years with an IDD diagnosis identified
- Demographic data were noted
- Independent variable: use of behavioral medication
- Dependent variable 1: current primary physician
- Dependent variable 2: dental care under general anesthesia

IDD Diagnoses

ICD-9	
277.5	Mucopolysaccharidosis
277.8x	Carnitine and metabolic myopathies
299.x	ASDs
315.x	Learning disability
317.x	Mild ID
318.x	ID, moderate or greater
319.x	ID, unspecified
330.x	Degenerative CNS disease
331.4	Hydrocephalus
333.7	Cerebral Palsy
335.21	Dystrophies
343.x	Cerebral Palsy
345.x	Epilepsy
359.0, 359.1, 359.21	Muscular dystrophies

ICD-9	
740.x	Brain malformations
741.x	Spina Bifida
742.x	Brain malformations
756.17	Spina bifida occulta
758.x	Trisomies and other chromosome anomalies
759.5	Tuberous sclerosis
759.81	Prader-Willi
759.83	Fragile X
759.89	Other genetic syndromes
760.71	Fetal alcohol
V79.2	"Mental retardation"
V79.3	Developmental handicap in childhood
V79.9	Mental handicap

Sample Search

i2b2 Query & Analysis Tool

Project: BARRIERS Project

User: sslukes

Find Patients | Analysis Tools | Harvard User Manual | Logout

Navigate Terms

Find

- Barriers to Transition for Youth with IDD Data
- Demographics
- Diagnoses
- Insurance
- Medications
- Procedures
- Providers
- Social History (In Development)
- Zip Codes

Workplace



Previous Queries

Find

- Ba-KAR-Eme-Unl@19:54:57 [4-25-2016] [sslukes]
- Barr-LIPSC-Unlis@16:13:59 [4-25-2016] [sslukes]
- Barrie-LIPSCHI@16:12:40 [4-25-2016] [sslukes]
- Unliste-LIPSCHI@15:31:18 [4-25-2016] [sslukes]
- Barrie-Dental @17:12:00 [4-6-2016] [sslukes]

Query Tool

Query Name: Ba-KAR-Eme-Unl@19:54:57

Temporal Constraint: Treat all groups independently

Group 1			Group 2			Group 3								
Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude						
Treat Independently			Treat Independently			Treat Independently								
Barriers to Transition for Youth with IDD Data			KARP, JEFFREY, DMD BERKOWITZ, ROBERT J, DDS MCLAREN, SEAN W, DDS DELUCIA, LISA M, DDS BARLETTA, DANIEL, DDS LIPSCHITZ, WAYNE, DDS			Emergency Department Services (99281-99288)								
one or more of these			AND			one or more of these			AND			none of these		

Run Query

Clear

Print Query

4 Groups

New Group

Show Query Status

Graph Results

Number of patients

67

For Query " Ba-KAR-Eme-Unl@19:54:57"

Results

- The variable of being on psychotropic medication as a proxy for behavioral problems does not correlate with delayed transition to adult primary health services
- % of participants on/off medications comparable and not stats significant
- Average age of the groups are the same from the group where they came ... not staying older with pediatricians
- Use of psychotropic meds did significantly correlate with use of GA for dental work

Policy/Action Impacts

1. Problem List Improvement
 1. Elimination of "R Word"
 2. Inclusion of functional info, e.g., communication, pica, wandering
2. "OPWDD" reminder in records, along with other coordination supports
3. Outreach to known providers
 1. Targeted point teaching
 2. Appreciation

Statewide Health Data Option 1: DD Agency

▪Pros:

- Captures people served by state + non-profit providers
- Everyone will have IDD
- Potentially common data dictionary
- Possible correlations with functional needs/services & supports

▪Cons:

- Only captures people registered with state
- Limited health data
- State may not want to/be able to share data
- Hard to compare to non-IDD sample

Survival Studies

Example: Eyman RK, Grossman HJ, Chaney RH, Call TL. American Journal of Diseases of Children 3/93, 147:329-336

11-year follow-up of 155,000 people served by California Dept. of Developmental Services, looking at survival based on functional factors

Findings:

Mobility improved survival

Tube feeding shortened survival

Statewide Health Data Option 2: Medicaid Claims

▪Pros:

- Captures people served by state + non-profit providers (if specially coded)
- Potentially broader than those just served directly by state
- Potentially broader common health data dictionary
- Potential to match with non-IDD sample within same dataset

▪Cons:

- Only captures people registered with state using special code (e.g., “-95” in NY)
- Limited correlations with functional needs
- Variable availability of data set; may need Health Department assistance
- Based on billing codes, so good only for services provided

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Example: ED Usage

Phillips KG, Houtenville AJ,
Reichard A. JIDR 4/19,
63(4):327-337

4 years of Medicaid claims data
in New Hampshire used to
compare those with/without
IDD and with/without
commercial insurance on ED
usage

	Medicaid			Commercial		
	No IDD <i>n</i> (%)	IDD <i>n</i> (%)	χ^2	No IDD <i>n</i> (%)	IDD <i>n</i> (%)	χ^2
Total claimants	108 369 (100)	4918 (100)		744 123 (100)	3910 (100)	
	Persons with ≥ 1 encounter			Encounters per person		
	IDD <i>n</i> (%)	No IDD <i>n</i> (%)	χ^2	IDD	No IDD	<i>t</i>
	Medicaid			* $p < .001$		
ED w/ admission	228 (9.50)	1911 (2.69)	380.65 [*]	1.73	1.18	9.83 [*]
ED w/out admission	1568 (65.31)	41 825 (58.86)	39.93 [*]	6.03	4.44	12.97 [*]
	Commercial					
ED w/ admission	87 (3.37)	1966 (1.16)	104.89 [*]	1.49	1.14	5.16 [*]
ED w/out admission	1131 (44.82)	63 935 (37.83)	149.49 [*]	3.94	3.06	10.24 [*]

Statewide Health Data Option 3: Health System Data

- Pros:
 - Very broad common health data dictionary
 - Good for assessing within one health system, potentially across multiple health systems
 - Potential to match with non-IDD sample within same dataset
 - Good for searching for both diagnosis and service data
 - Good for looking at services provided to people with IDD in more generic settings
- Cons:
 - Problem Lists: GIGO
 - Limited correlations with functional needs
 - Better for hospital-provided services, less good for primary care settings

Statewide (or Nationwide*) Health Data Option 3: Health Care Systems

Turk, Landes, et al. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. Disability and Health Journal (2020) 13:1-4

TriNetX: Data mining from medical centers in NY and nationwide

More, worse COVID in younger patients with IDD



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Real-world data and evidence that runs a mile wide...

250M+

patient lives

120+

healthcare organizations providing continuous, comprehensive, up-to-the-month data

19

countries in North and South America, EMEA, and Asia-Pacific

...and a mile deep.

70B

date- and patient-specific clinical observations available for download

122

lab results in the typical record of U.S. and EMEA patients

5+

years of clinical history on more than 40 million patients around the globe



Policy/Action Impacts

1. Outreach to known providers
 1. Targeted point teaching
 2. Appreciation
2. Government policies: COVID hospital admission/visitation
3. Agency policies: example: Dysphagia/Choking protocol

Questions??



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